

## State Plan for Alzheimer's and Related Disorders Working Group

### Access Sub-Group

Second Meeting

November 1, 2012

RICCMHO

**Present:**Maureen Maigret (Chair), Marie Carpenter (Director of Elder Care Services, American Baptist Churches), Laurie Johnson (OHHS), Valerie Topp (Home Instead) Lola Okunfolami (PACE), Annie Murphy (Alzheimer's Association), Dr. Brian Ott (RIH)

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1. Maureen Maigret began with suggestion that we go over the minutes from the prior meeting. **She also shared RIPTA's "How to Ride Guide," which was created in partnership between AARP and RIPTA.** This guide explains regular service and special service. **She also mentioned the Wheelchair Available Taxis, which charge the standard rate.** There is a number for each taxi company.
2. Valerie brought up the challenge of getting someone to the appointment from the curb. The cab service is still just a curb only service.
  - a. **This touches on a problem we discussed at the last meeting, which is that the RIPTA services take people to the door, but navigating from the door to the suite or specific office is a real challenge.** We discussed the possibility of working with hospitals transport services to see if it's possible to meet people to get them where they need to go within the building. Lindsay will follow up on this as a potential future meeting (what facilities have this/who doesn't? Is this a feasible recommendation – a "curb to counter" escort?)
  - b. Dr. Ott mentioned that they have a valet service at their Ambulatory Patient Center Services building. When you make an appointment and mention they're coming for the RIH Memory Center, the person calling is told about the service.
  - c. The main hospital doesn't have this service. Cancer Center and Dialysis patients also get the valet service. **Physical or cognitive disabilities are served by this program at RIH.**
3. Maureen then introduced Dr. Ott and explained that we're looking at pathways to care – when is it advisable to seek a specialist or broach the idea of going to a center like the Memory Center?
4. Dr. Ott responded that the first place to start is within the primary care office. Not all primary care physicians (pcp's) are committed or sensitive to cognitive problems.
  - a. **There tend to be two types of pcp's: those that will attend to a cognitive issue like many other medical issues that come across their desk (and within this group, about half may manage Alzheimer's Disease throughout the continuum of the disease fairly well and others may refer out); the other group is that which will treat physical ailments and not mental or cognitive at all - they won't screen them or test them, but may refer them out for an initial evaluation.** This second

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group is where doctors aren't recognizing AD at all and won't treat it. This spurs self-referral if the family or individual isn't getting the care they need from their pcip. **The Memory Center will take people by self-referral, but they prefer not to.**

5. Marie Carpenter asked if someone comes in on self-referral, will you work with their pcip?
  - a. Dr. Ott responded that they will and 95% of the time the pcip will cooperate.
6. **Maureen Maigret asked if there's a particular screening tool that is recognized as a best practice?**
  - a. **Dr. Ott shared that he typically recommends a formal mental status screen.** That said, this is a lot to ask physicians and if they only have 20 minutes to treat their diabetes and hypertension, they may run out of time.
7. Annie Murphy asked if there is a status or an age that triggers a recommendation for a dementia screening?
  - a. **Dr. Ott: no its still controversial as to whether to do an Alzheimer's screening in the pcip office.** There is no compelling reason to make pcips do a mental status examination.
8. **At RIH there is a pilot looking at those admitted for confusion to trigger a mental status examination.**
9. **Maureen Maigret added that with the push towards medical homes and employment that is part of that for nurse case managers, they would be in a good position to execute either the mini-MoCA or mini-mental status test and Dr. Ott agreed that is something that would make a lot of sense.**
10. Viewpoints and papers on screening, many favor doing so for people to complain of a problem but not everyone.
11. Maureen Maigret asked if there has been a dialogue between pcip's, your field, etc. to encourage that type of screening? Dr. Ott did not feel there had been to date. Lindsay will raise this with the Research sub-group.
12. Maureen Maigret: With regards to an annual wellness screen: usually substance abuse, fall risk, depression – they're set up as part of the electronic screening to trigger the question.
  - a. AMA and a larger group are recommending cognitive screening questions as part of any EMR format. Safety, palliative care, -- recommendations for improved performance, but aren't incorporated anywhere as the standard of care yet.
13. Maureen Maigret asked Dr. Ott to explain what is done in a Memory Center – they're a specialty center and do special assessments (1-2 hours). They take a historical and physical exam. Formal assessment of depression on everyone. They also do a memory screen to determine if mild or early, etc.
  - a. Naming task, work fluency task, cognitive and work up take half the time. Functional history rated on clinical dementia rating scale.
  - b. **This helps to encourage communication across memory clinics – the measures are standard across them all.**
14. **Someone asked what the test is that helps you distinguish between mild and normal dementia:**

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- a. The answer was that you read a story about someone and then there are 25 elements you should remember immediately and come back half an hour later (education adjusted norms are incorporated) and are asked to recall those elements.
  - b. **This tool is for someone who recognizes they're not remembering as much as they used to. It helps to figure out if its normal age-related condition or cognitive impairment.**
15. The Memory Center is concerned about early intervention. People come in when they're just concerned or complaining about their memory and are trying to figure out if its "normal or a problem."
16. Maureen Maigret asked how people are recommended for clinical trials?
- a. **Dr. Ott explained that they're co-located so there's a lot of cross-talk, social workers, nurses and clinical researches are all cross talking. If they're treated with prescriptions and its not working, then they are told about the programs available – they can just walk across the hall and find out.**
17. **Marie Carpenter inquired whether pcps have information on clinical trials and Dr. Ott answered that they do, but in his view, they never refer people.**
18. **Annie Murphy shared that the Alz. Association offers the trial match program. This is one avenue that can link people to the clinical trials.** It's a database – you can connect to the national association and get a clinician who will ask you certain questions and then they'll give you data information on trials you may be eligible to participate in.
19. Dr. Ott added that there is also an Alzheimer's Prevention Registry. If you wait until people are demented and going to a clinic, you're probably too late. Can't draw from people for research from the clinic forever, need earlier folks. The registry is for people who can be part of the prevention registry.
20. **Maureen Maigret asked Dr. Ott to explain what a recommendation would be if someone comes in and they have mild cognitive impairments?**
21. **Dr. Ott explained that this is the most frequent diagnosis. We then follow them going into the phases of dementia and this is the best way to do it.** You can now do a test to know if you're at high risk of going further into the disease faster or not. Some don't want to know, but others are very interested in treatment. We can do tests that help to diagnose alzheimer's disease when you're not demented. Biomarkers and biological tests for plaques and tangles, getic, brain imaging, spinal fluid, neuropsychological tests too. For those cases where we think they're already at that point or will be soon, they'll be treated with Alzheimer's medications. Watchful waiting.
22. Maureen Maigret asked how often would someone visit and Dr. Ott responded that a routine follow up is every 6 months. For mild, it is every year.
23. **Maureen Maigret asked about coordination and Dr. Ott said that there's a letter sent to the pcps. There are pcps who do this hand off or coordination better. Alz Association can refer them.**
24. People coming to a memory clinic want to know – they're proactive. We're seeing more folks coming in so that shows a trend that people want to know – part of this is education and it used to be treatment availability. There are drugs to treat

- Alzheimer's now – there are more drugs available. Testing to identify the disease has become so much better and treatments treat underlying issues which is also encouraging.** The promise of what is coming and education and public information about what memory loss is ... recognizing there's a phase where you're aware of memory loss and its mild and you're just dealing with it. **People are realizing that once you're aware of it, you benefit from being educated and being proactive rather than stressing and depressed.**
25. Annie Murphy added that education and knowledge is power. Families with Alzheimer's in their history want to know how to help themselves and their families and prepare for down the road. They see that people want to take care of themselves to better position health-wise. They want control over their own health issues.
  26. **Dr. Ott agreed that that is the key; the concept of people wanting to manage their risk factors. They know from their genetics and to know they can do stuff to keep their brain healthy is huge. Living a vigorous physical lifestyle to keep brain healthy... the Prevention Registry provides a newsletter quarterly talking about risk factors and things you can do to change diet and lifestyle – this is very attractive to people.**
  27. **Maureen Maigret added that longevity is an issue now for women and those in their eighties have dementia at a rate of 47%. Age 78 is the mean lifespan for women and for men its 73. Women become the primary caregivers.**
  28. **Maureen then asked that given that any Alzheimer's center would put someone through standard set of testing is this the same of they go to private neurologist? Would they get a standard test? Dr. Ott said no. If they're trained by us, then yes.**
  29. Maureen Maigret added that a pcp who is likely to refer would they be more apt to refer to a memory center or a private neurologist?
  30. Dr. Ott said that he is unsure, but probably they refer to their own network of specialist.
  31. Lola Okunfolami asked about the gender and age of those who go to Dr. Ott's Memory clini and Dr. Ott said that the average is 72 and gender is probably 55% women 45% men, likely 12 years plus education.
  32. **Maureen Maigret asked about the different stages of alzheimer's given that there is confusion or references to different stages depending on the article. Dr. Ott said that the clinical dementia ratings are: normal, questionable, moderate or severe. There are different staging systems but it's a continuum and this complicates the use of staging.**
  33. **Maureen Maigret dsif there's always a discussion of when people are safe in a regular assisted living facility versus when they need to be in a special care unit and there doesn't seem to be a good way to determine when they need to be moved to be in compliance with state regulations and their own safety. She asked if Dr. Ott felt there's a good way to determine when a person has the judgment to know when they're safe and can act appropriately in an emergency.**
  34. **Dr. Ott said he felt that there isn't. It's a gray area. There are extremes, but there are many people who are mild who shouldn't be on the road.**

35. **Valerie Topp said that one challenge is the family who may not see that the person needs to be moved.** The Assisted Living facility is struggling to work with the family members and the reason she's aware of this is that they use Home Instead to ensure the safety of the person with dementia.
36. **Maureen Maigret added that you could use these guidelines and refer to deficiencies more concretely. She then asked about reimbursement in the Memory Center...**
37. **Dr. Ott explained that it's covered by regular co-pays despite the fact that it's more than a regular evaluation. It is covered by Medicare. No special reimbursement for the extra care provided.**
38. **Maureen Maigret: there may be people on Medicaid – does Medicaid cover your Center?**
39. **Dr. Ott – yes. There is some restriction as to services you may want for neuropsychiatric testing – a long wait or places where you may not be seen (just like general medical care).**
40. Maureen Maigret raised the final topic of driving.
41. Annie Murphy explained that some of the questions came up around someone who has cognitive impairments and the question is always when the family member wants to take away the keys.
42. Dr. Ott: there is a consensus that people with moderate dementia should not drive as measured by this dementia rating I'm talking about. If you need help with all of your daily living activities, you shouldn't be driving.
43. Annie Murphy: how does dementia impact driving and what are some of the concerns?
44. Dr. Ott: people have challenges dealing with seeing multiple things at once, such as a red light and cars coming – such as making a left hand turn at a light and seeing the cars oncoming. The increased crash risk is 2-5 times more likely per mile driven. Luckily, they aren't typically driving too far. There are also people who are over-concerned. It is not palatable that people with early dementia can actually drive. **It should be based on performance-based assessment that measures whether you're at risk. Do a road test. We have a list of instructors and companies that do these tests. It has a lot of base validity. The instructor can pass you for 6 months to a year and then get reevaluated. This costs money. It runs from \$150-400. You can shop around a little.**
45. Lindsay McAllister asked who developed the test and Dr. Ott answered that the road test is a bit artificial because people are nervous and are on their best behavior.
46. People have different ways of doing the test and different levels of expertise in evaluating the senior. You can be a road instructor without certification – you have to have your license and pay a fee.
47. **Annie Murphy asked if he would recommend going to the same person for the follow-up test?**
48. **Dr. Ott answered yes, probably.**
49. Maureen Maigret asked if there is a standard assessment?

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50. Dr. Ott: For research, yes. **If you go to a regular road test they'll do their own. Our researcher will go with a person to their own neighborhood and drive around for a few hours.**
51. Annie Murphy asked if he's noticed a difference between the older generation and the younger generation with the disease being more willing to give up their keys? We've noticed the younger folks are more willing.
52. Dr. Ott: I haven't noticed that.
53. Maureen Maigret: recommend the 55+ driving program from AARP. A classroom wouldn't be that helpful for the oldest.
54. Dr. Ott: a video recording used for teens to keep them safer – its also used with truck drivers – whenever you break, swerve, etc. it begins recording and its sent out to the internet and the information is given to the patient and family to view every week to use as an assessment tool. "Drive Cam."
55. **Annie Murphy added that many families use the physician relationship to help facilitate this conversation. If they push back, they recommend a road test with a private company.**
56. Dr. Ott: went to the DMV and they reviewed cases every few months. **Encouraged them – if doctor recommends – to do a road test and not just pull the license. DMV workers aren't trained to assess people with dementia – they're trained to evaluate teens – you're probably better off going through a private instructor! The benefit of the state is that it's free.**
57. **Laurie Johnson: basic inventory mental status (BIMS) is being used by the minimum data set – the nurses send us evaluations for the MDS recommending BIMS.**
58. **Dr. Ott: its better than not doing any standardized assessment, if you're trained to use the instrument. Nursing homes use different tools than what we use in practice. It probably makes sense to use something different in a different setting.**
59. Dr. Ott was asked whether his your practice deal with dual diagnosis?
60. He answered "not well", there should be a specialty clinic set up for those people who have down syndrome because they're a special group, but there are fractures within the care delivery system in terms of people getting together and coordinating.
61. **Cathy Salerno added that she was hopeful the Living Rite Centers will have tools there.** Many with Down Syndrome cannot read or follow a story to be able to help a doctor diagnose dementia. Hopefully we'll be able to get some tools to help that population. Potentially an opportunity to work together on a tool to diagnose – Molly Tracy a pediatric neurologist at RIH would be the person to contact.
62. Dr. Ott shared that average waiting time is 4 weeks and for him, its 6 weeks – under 2 months is what they strive for.
  - a. **Need an add-on code – which pays less than the office visit? – for doing the mini-mental exam. A way to pay for that time is huge.**
63. Working toward being a medical home should incorporate the administration of this test by the nurse case manager or the licensed social worker.

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- Dr. Ott emailed the Driver Test Referral List and Dementia Performance Measurement Set on 11/7/12 to Maureen and Lindsay.
- The meeting was adjourned.